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ABSTRACT

The present guidelines have been prepared to provide counselors, health care workers, and others with a model for use in counseling people affected directly or indirectly by Human Immunodeficiency Virus (HIV) infection and Acquired Immune Deficiency Syndrome (AIDS). The guidelines describe the nature, role, and principles of counseling, the psychosocial repercussions of HIV infection and associated disease, and special situations in which counseling is indicated. Whatever the overall HIV/AIDS prevention and control strategy, counseling should be a major integral part. The specific counseling activities will depend on the individuals and groups to be addressed, the content to be emphasized, and the manner in which counseling is to be provided. The booklet's introduction describes the three AIDS-related epidemics. Clinical manifestations, transmission, global epidemiological patterns, and prevention control activities are discussed. The target audiences for HIV/AIDS counseling, where the counseling can be provided, and by whom and why are discussed. The main functions of counseling: prevention, and psychosocial support are then presented. Requirements of counseling, including essential features of counseling, and counseling activities are examined. The components of counseling before and after HIV testing or screening are differentiated and the needs of significant others are defined. Special issues such as pregnancy, infants with suspected HIV infection, breast-feeding, children in school, HIV-infected children with hemophilia, and the workplace are also discussed. (LLL)

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WHO

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SERIES

8

GUIDELINES FOR COUNSELLING ABOUT HIV INFECTION AND DISEASE

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The World Health Organization is a specialized agency of the United Nations with primary responsibility for international health matters and public health. Through this organization, which was created in 1948, the health professions of some 165 countries exchange their knowledge and experience with the aim of making possible the attainment by all citizens of the world by the year 2000 of a level of health that will permit them to lead a socially and economically productive life.

By means of direct technical cooperation with its Member States, and by stimulating such cooperation among them, WHO promotes the development of comprehensive health services, the prevention and control of diseases, the improvement of environmental conditions, the development of health manpower, the coordination and development of biomedical and health services research, and the planning and implementation of health programmes.

These broad fields of endeavour encompass a wide variety of activities, such as developing systems of primary health care that reach the whole population of Member countries; promoting the health of mothers and children; combating malnutrition; controlling malaria and other communicable diseases, including tuberculosis and leprosy; having achieved the eradication of smallpox, promoting mass immunization against a number of other preventable diseases; improving mental health; providing safe water supplies; and training health personnel of all categories.

Progress towards better health throughout the world also demands international cooperation in such matters as establishing international standards for biological substances, pesticides, and pharmaceuticals; formulating environmental health criteria; recommending international nonproprietary names for drugs; administering the International Health Regulations; revising the International Classification of Diseases, Injuries, and Causes of Death; and collecting and disseminating health statistical information.

Further information on many aspects of WHO's work is presented in the Organization's publications.

WHO AIDS Series **8**

Guidelines for counselling about HIV infection and disease

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Contents

	Page
Preface	v
1. Introduction	1
The three AIDS-related epidemics	1
Clinical manifestations	2
Transmission	4
Global epidemiological patterns	6
Prevention and control activities	8
2. What is counselling?	10
Who is HIV/AIDS counselling for?	11
Where can HIV/AIDS counselling be provided?	11
Who should provide HIV/AIDS counselling?	11
Why is counselling about HIV necessary?	12
3. The main functions of counselling	14
Prevention	14
Psychosocial support	16
4. Requirements of counselling	18
Essential features of counselling	18
Counselling activities	19
5. Counselling before HIV testing or screening	22
The aim of pre-test counselling	22
Issues in pre-test counselling	22
If testing is not available	24
6. Counselling after HIV testing or screening	25
Counselling after a negative result	25
Counselling after a positive result	25
Counselling after an equivocal test result	31
Self-help groups	32
7. Needs of significant others	34
Health workers	34
The family	34

8. Some special issues 36
Pregnancy 36
Infants with suspected HIV infection 36
Breast-feeding 37
Children in school 38
HIV-infected children with haemophilia 38
The workplace 39
Annex 1. Instructions for condom users 40
Annex 2. Guidelines on prevention of sexual transmission of HIV 41
Annex 3. Practical information for people with HIV infection or disease 45

Preface

The World Health Organization places high priority on developing strategies to prevent and control infection with the human immunodeficiency virus (HIV), in which information, education and communication (IEC) play a fundamental role. Counselling is recognized as a vital part of an overall IEC-based strategy, but work with over 160 Member States in support of national programmes to combat acquired immunodeficiency syndrome has shown that this is a relatively new concept in many parts of the world, especially when proposed as a routine service. To facilitate the development of counselling services and to provide a standardized basis for counselling, WHO has instituted a series of training and operational research activities.

The present guidelines have been prepared to provide counsellors, health care workers, and others with a model for use in counselling people affected directly or indirectly by HIV infection and AIDS.

The guidelines describe the nature, role, and principles of counselling, the psychosocial repercussions of HIV infection and associated disease, and special situations in which counselling is called for. They should be adapted to the human and technical resources and, particularly, the cultural traditions of the societies in which they are used.

The World Health Organization thanks all the people – counsellors, health workers, health planners, educators and people with HIV infection – who contributed to these guidelines. Particular mention should be made of the following: Dr Manuel Carballo, Chief, Social and Behavioural Research, Global Programme on AIDS, WHO, Geneva, Switzerland; Dr Alfred Chingono, Counselling Coordinator, Ministry of Health, Harare, Zimbabwe; Dr Brigitte Gredler, formerly Regional Programme on AIDS, WHO Regional Office for Europe, Copenhagen, Denmark; Dr John Green, Head, National AIDS Counselling Training Unit, St Mary's Hospital, London, England; Mrs Noerine Kaleeba, Director, The AIDS Support Organization, Kampala, Uganda; Dr Gary A. Lloyd, Professor and Coordinator, Institute for Research and Training in HIV/AIDS Counselling, Tulane University, New Orleans, LA, USA; Dr David Miller, Global Programme on AIDS, World Health Organization, Geneva, Switzerland; Mrs Riva Miller, AIDS Counselling Coordinator, Hampstead Health Authority and Senior Social Worker, The Royal Free Hospital, Hampstead, London, England; Dr Mercy Montsi, Institute of Education, National University of Lesotho, Roma, Lesotho; Dr Jan-Olof Morfeldt, President, Noah's Ark–Red Cross Foundation, Stockholm, Sweden; Professor David M. Ndeti, Chairman, Department of Psychiatry, University of Nairobi, Nairobi, Kenya; Ms Virginia O'Dell, Global Programme on AIDS, World Health Organization, Geneva, Switzerland; Dr John M. Sketchley, Education Adviser to the General Council and Register of Osteopaths, Reading, England; Ms Françoise Weil-Halpern, Psychologist, Necker Hospital for Children and Sick People, Paris, France.

1. Introduction

The three AIDS-related epidemics

Acquired immunodeficiency syndrome has produced not one but three related worldwide epidemics that must be prevented or controlled – HIV infection, AIDS and other clinical manifestations of infection, and the social, cultural, economic, and political reaction and response to the first two epidemics.

HIV infection probably began to spread in the 1970s. By early 1990, an estimated 6 million people throughout the world had been infected with HIV, and further spread is inevitable. Cases of the disease AIDS and other clinical manifestations of HIV infection were first reported in the United States of America in 1981. However, AIDS is known to have occurred in several other areas of the world before that. By 30 September 1990, a total of 288 337 AIDS cases had been reported officially from Africa, the Americas, Asia, Europe, and Oceania. However, for a variety of reasons such as under-recognition, underdiagnosis, and under-reporting, the actual total is probably around 600 000. Moreover, the number of AIDS cases is a misleading guide to the seriousness of the situation; because AIDS develops only some years after a person acquires HIV infection, today's AIDS cases reflect the level of HIV infection 3–5 or even more years ago. It is estimated that for every AIDS case, 25–100 people may be infected with HIV; this ratio is likely to decrease in the next few years.

A steep increase in the number of AIDS cases is being observed throughout the world. Of the at least 6 million HIV-infected people, it is estimated that 10–30% will develop AIDS during the next 5 years. Thus, between 600 000 and 1 800 000 people already infected with HIV will develop AIDS by 1995.

The third epidemic – the intense global reaction to AIDS and HIV – is just beginning. Fear and ignorance are having severe effects at the personal, family, and social level. HIV-infected persons, including those with AIDS, are often excluded from the family and community at a time when they most need support and care.

In contrast to most health problems, which affect either the very young or the elderly, AIDS strikes mainly those in the age group 20–49 years. By depriving the community of people in their most productive years, AIDS poses a serious threat to social and economic development and even to political stability. As the number of AIDS cases rises steeply over the next few years, the economic, social, political, and cultural effects will be dramatic. In industrialized countries, the cost of direct medical care for a person with AIDS is estimated at between US$ 25 000 and US$ 150 000. In the developing world, the additional burden of AIDS on already strained health resources will be enormous, especially in countries where the annual per capita health budget is only a few dollars.

AIDS also affects mothers and children. In some areas, the increase in infant mortality from HIV infection may offset the progress being made in child health programmes. Thus AIDS threatens many of the health gains projected for the developing world.

The social and economic stresses associated with HIV and AIDS have become a major political and cultural issue. Fear of AIDS threatens to restrict travel and communication among countries. In many countries and communities there is still a tendency to stigmatize specific groups, races, and nationalities. HIV and AIDS may threaten the fundamental values of society, and any attempt to deal with them presents a formidable challenge.

Clinical manifestations

Pathogenesis

HIV, the causative agent of AIDS, selectively infects specific white blood cells (CD4 cells) that are essential for the body's immune defence system. When the CD4 cells are destroyed, the infected person becomes susceptible to a range of opportunistic infectious diseases and cancers. AIDS is the term applied to a group of such conditions, the presence of which indicates severe damage to the immune system. HIV may also directly infect nerve cells, causing neurological disturbances. HIV infection is presumed to be lifelong and the infected person is likely to remain infectious for life.

Rate of progression to AIDS

Initially it was thought that only a small proportion (5–10%) of HIV-infected persons would develop AIDS. Today, there is evidence that about 20% of those infected will develop AIDS within 5 years of becoming infected, and about 50% within 10 years. An increasing proportion will probably go on to develop AIDS after 10 years, as people with HIV infection show progressive damage to their immune system over time. However, the exact numbers are difficult to determine since there has been less than 10 years of follow-up on most groups of HIV-infected persons.

Manifestations

The clinical signs and symptoms of HIV infection are many and varied; they include the opportunistic infections and cancers as well as symptoms caused directly by HIV itself.

The natural history of HIV infection can be divided into four different stages, although all four do not necessarily occur in all infected individuals. In stage 1, the patient is either asymptomatic or may present with persistent generalized lymphadenopathy, while stages 2, 3 and 4 may be referred to, respectively, as "early", "intermediate", and "late" disease.

Acute prodromal manifestations

Acute HIV disease can occur as early as a few weeks after the infection is acquired. It generally precedes the development of an antibody response (seroconversion), which usually occurs in the first 6–12 weeks after infection. The period before the development of an antibody response is often referred to as the "window" period, when the person is infectious but tests for antibody do not show it. The typical clinical manifestations in the acute phase are fever, lymphadenopathy, night sweats, skin rash, headache, and cough.

Stage 1

The duration of this phase, in which the patient is either asymptomatic or presents with persistent generalized lymphadenopathy (PGL), can range from a few months to many years. PGL is characterized by lymph node enlargement to greater than 1 cm in diameter, involving two or more extrainguinal sites, and lasting for at least 3 months, in the absence of any other current illness known to cause lymphadenopathy. PGL may slowly regress during the course of the disease.

Stage 2 (early disease)

This stage is characterized by the occurrence of typical mucocutaneous lesions, such as oral hairy leukoplakia, or infections such as zoster. "Constitutional" manifestations, such as moderate weight loss, fatigue, anorexia, and night sweats, are also common in stage 2. These signs and symptoms are frequently intermittent. Recurrent upper respiratory tract infections may also occur during this phase of the disease.

The types of opportunistic infection depend largely on the past and current exposure of the individual to microbial agents. This is the reason for the differences in the frequency of certain opportunistic infections between African and American or European HIV-infected patients.

Stage 3 (intermediate disease)

Clinical manifestations characterizing stage 3 may occur more frequently some time after the early symptoms but before the full development of late-stage indicator disease. Stage 3 clinical conditions typically include oral candidiasis, oral hairy leukoplakia, pulmonary tuberculosis, labial or genital herpesviral vesicular dermatitis, isosporiasis, some bacterial infections such as alveolar pneumonia, a tumour (Kaposi's sarcoma) that is very characteristic of HIV infection, and a number of constitutional symptoms such as persistent fever, diarrhoea, and weight loss exceeding 10% of body weight.

Stage 4 (late disease)

In this stage, the most commonly occurring opportunistic infections have a particularly severe course because of the profound immunosuppression of

the host. Commonly occurring infections may be protozoal (*Pneumocystis carinii* pneumonia, toxoplasmosis), fungal (visceral and oesophageal candidiasis, cryptococcosis), bacterial (atypical mycobacteriosis, salmonella septicaemia), or viral (cytomegalovirus, progressive multifocal leukoencephalitis). Particularly severe forms of lymphoma and cachexia may also occur during this late stage of the disease.

Neurological manifestations

Neurological abnormalities, such as peripheral neuropathy and memory loss, are being increasingly documented in people with HIV infection. In some patients, they may be the first manifestation of HIV infection and are often atypical in their presentation.

The most frequent neurological disorder is a subacute encephalopathy characterized by progressive behavioural changes associated with dementia; it occurs in approximately one-third of people with late-stage HIV infection. Its onset is usually insidious, and cognitive dysfunction predominates initially. Common early signs include tremor, slowness, and aphasia. The course is usually progressive towards severe dementia. Mutism, incontinence, loss of vision, and paraplegia may develop in the terminal stages.

Other causes of neurological manifestations in people with HIV infection include, as mentioned above, cryptococcal meningitis, cerebral toxoplasmosis, lymphoma of the brain, and papovavirus and cytomegalovirus infection.

Manifestations in infants and children

A substantial proportion of infants who contract HIV infection from their mothers (before, during, or shortly after birth, or possibly through breastfeeding) or from blood transfusions generally show symptoms by about 6-12 months of age. Children with AIDS survive, on average, about 18 months after the first signs appear. Clinical manifestations include failure to thrive and to reach neurodevelopmental milestones, with the appearance of neurological manifestations in many HIV-infected infants. Weight loss, diarrhoea, oral and oesophageal candidiasis, pneumonia, and fever are common. However, these signs and symptoms also represent common background illnesses in this age group and make the clinical diagnosis of AIDS in children very difficult.

Transmission

HIV has been isolated from the body fluids of infected persons, including saliva and tears; however, only blood, semen, vaginal secretions, and breast milk have been implicated in transmission. Detailed epidemiological studies throughout the world have documented three modes of transmission: sexual, parenteral, and perinatal.

Sexual transmission

On a global basis, sexual intercourse is the most frequent means of transmitting HIV. The virus can be transmitted from an infected person to his or her sex partner (man to woman, woman to man, and man to man). People who abstain from sex and people who are not infected and have sexual intercourse only with a monogamous uninfected partner are not at any risk of becoming infected sexually with HIV.

To reduce the risk of acquiring HIV sexually, people must take specific steps, including:

- reducing the number of sex partners (the more partners, the greater the potential risk);
- avoiding sex with people who have many sex partners (e.g., prostitutes);
- using a condom from start to finish for all sexual penetration (vaginal, oral, and anal).

Instructions for condom users are presented in Annex 1, and guidelines on safer sexual practices are presented in Annex 2.

Parenteral transmission

Parenteral transmission occurs through the transfusion of infected blood or blood products, or the use of blood-contaminated needles, syringes, or other skin-piercing instruments. The risk of acquiring HIV infection is related to the size of the inoculum: recipients of a single unit of HIV-infected blood have virtually a 100% probability of acquiring infection.

Transmission through blood transfusion is a significant problem in countries where HIV infection is common and where nationwide HIV antibody screening of blood donors has not yet been established. Transmission through HIV-contaminated needles and syringes is an especially significant problem among users of intravenous drugs, and where needles and syringes are not sterilized before reuse.

Perinatal transmission

Transmission of HIV infection from a woman to her fetus or infant may occur before, during, or shortly after birth. The overall risk of HIV transmission *in utero* or during delivery is 20–40%. Postnatal transmission (probably through breast milk) has been described in a small number of infants of mothers who acquired HIV infection after delivery.

There is no evidence to indicate that HIV can be transmitted by the respiratory or gastrointestinal routes, or by casual person-to-person contact in the home or elsewhere.

There is no evidence to suggest that HIV can be transmitted through insects, food, water, toilets, swimming-pools, sweat, tears, shared eating and drinking utensils, or other items such as telephones or second-hand clothing.

Global epidemiological patterns

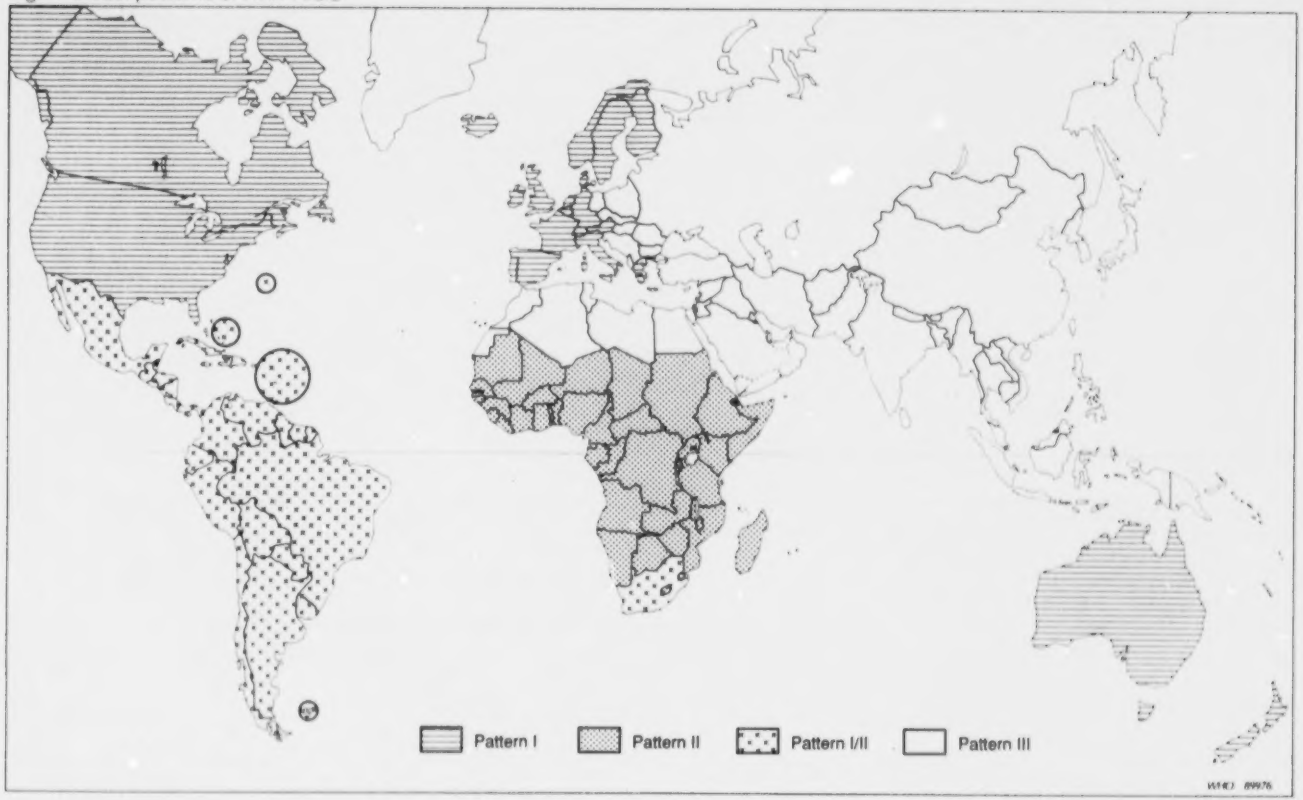
The epidemiological data available on the distribution of AIDS throughout the world point to several distinct patterns, each of which is characterized by the time of the disease's appearance and the predominant modes of transmission (Fig. 1). The epidemiological pattern has implications for the type of prevention and care activities called for, and for the priority that needs to be given to different aspects of those activities.

Pattern I

In pattern I areas, most cases of HIV infection and AIDS occur in homosexual or bisexual males and intravenous drug users. Extensive transmission of HIV appears to have started in the late 1970s. Heterosexual transmission is increasing but is responsible for only a small percentage of cases. Transmission through blood and blood products has been reported, but has now largely been controlled by the voluntary exclusion from giving blood of persons with risk behaviour and/or routine HIV screening of blood donors. The male-to-female ratio of AIDS cases ranges from 10:1 to 15:1. In the general population, HIV prevalence is usually well under 1%, but it can be over 50% in groups with high-risk behaviour. This pattern is typical of North America, Western Europe, Australia, and New Zealand.

The epidemiological pattern in many countries initially classified as pattern I is still evolving. For example, in many Latin American countries, since the middle of the 1980s, increasing transmission among heterosexuals with multiple sex partners has been noted, to such an extent that this mode of transmission has become predominant. As a result of this shift, Latin America has been reclassified as pattern I/II.

Fig. 1 Global patterns of HIV/AIDS



Pattern II

Pattern II is typical of most of sub-Saharan Africa and parts of the Caribbean. Most cases in these regions occur through sexual transmission among heterosexuals, and the male-to-female ratio of cases is about 1:1. As a result, transmission from infected women to their fetuses or infants is common. Extensive transmission appears to have begun in the mid- to late 1970s and, in a number of countries, the overall population seroprevalence of HIV may now be more than 1%. Transmission also occurs through blood transfusion, the use of unsterilized needles and syringes, and other skin-piercing practices. The principal mode of transmission, however, continues to be sexual. Transmission from injecting drug users and male homosexuals is either absent or occurs at a very low level. In some urban areas, up to 25% or more of the sexually active age group is infected.

Pattern III

In pattern III areas, HIV appears to have been introduced in the early to mid-1980s and only small numbers of AIDS cases had been reported as of 1989. Both homosexual and heterosexual transmission are currently being reported. Most early cases were imported as a result of travel in, or contact with individuals from, endemic areas, or were caused by imported blood products. In some pattern III areas, the situation has begun to change rapidly. In Thailand, for example, evidence suggests rapid indigenous spread of HIV in the past 2 years associated with intravenous drug use. The pattern is found in North Africa, Eastern Europe, the Eastern Mediterranean, Asia, and most of the Pacific area.

Prevention and control activities

In each region and country, the need for HIV/AIDS prevention and control activities has become of paramount concern to public health authorities. The character and content of the prevention and control programmes will depend on the local nature, magnitude, and distribution of the epidemic. Such programmes should be responsive to the epidemiological features of the problem and the profiles of the population groups most affected. As with all well designed public health strategies, they should also respond to the social and cultural characteristics of those groups, their dominant risk behaviour, their accessibility, and their likely participation in activities to reduce risk.

Whatever the overall HIV/AIDS prevention and control strategy, counselling should be a major integral part. The specific counselling activities will depend on the individuals and groups to be addressed, the content to be

emphasized, and the manner in which counselling is to be provided. In addition, the availability of technical resources, financing, and an infrastructure within which counselling can be provided will all need to be taken into account.

Nevertheless, certain basic principles can be applied to all situations:

1. Counselling has to be part of all strategies for preventing HIV infection. Most people with HIV infection do not know that they are infected. Until now, only a small percentage of those with identified HIV infection or disease have had access to reliable counselling services and, therefore, to support for the necessary changes in behaviour. The continued development of counselling services is therefore important to the prevention of HIV.

2. Counselling should be an integral part of all HIV testing, screening, and health care programmes. In many areas, counselling can be provided in the context of established health outreach, primary health, or clinical care programmes, such as through sexually transmitted disease clinics, medical or surgical services, antenatal and postnatal clinics, and family planning clinics.

3. For health workers to acquire the skills needed for HIV/AIDS counselling, training programmes will be required. All health care programmes dealing with HIV-infected people should include counselling and appropriate counselling training for staff.

Nongovernmental organizations (NGOs) and peer-led AIDS service organizations (ASOs) should be actively and closely involved in counselling.

2. What is counselling?

HIV/AIDS counselling is an ongoing dialogue and relationship between client or patient and counsellor, with the aims of: (1) preventing transmission of HIV infection and (2) providing psychosocial support to those already affected. In order to achieve these objectives, counselling seeks to help infected people make decisions about their life, boost their self-confidence, and improve family and community relationships and quality of life. HIV/AIDS counselling also provides support to the families and loved ones of infected people, so that they in turn can provide encouragement and care for those with HIV infection.

Prevention and support are complementary processes. In HIV counselling, efforts to prevent transmission that are not accompanied by some type of support are unlikely to be effective. Messages regarding prevention are always more readily accepted when they are made personally relevant to the individual's needs and life-style. The way in which messages are provided in a counselling context should also promote a feeling of trust and understanding that helps the person to make, and sustain, appropriate changes in behaviour.

If people are to modify their life-styles in response to the information they receive, they will need a strong sense of individual responsibility. Counselling attempts to help people define for themselves the nature of the problems they face and make realistic decisions about what they can do to reduce the impact of those problems on themselves and their family and friends.

The techniques used in counselling will vary from country to country, and perhaps within countries, according to the background of the people being counselled and the type of health or social services that are available locally. Effective counselling need not follow any set pattern or approach. It certainly need not be restricted to a clinic or a structured doctor–patient situation. The most successful counselling often takes place outside the context of formal relationships.

Counselling nevertheless involves much more than a single or occasional informal discussion. Most people affected by HIV need continuing support and help with problem-solving, which will be key aspects of most counselling relationships.

Who is HIV/AIDS counselling for?

In the context of HIV infection and AIDS, counselling is appropriate for the following:

- people worried that they might be infected with HIV;
- people considering being tested for HIV;
- people who have been tested for HIV (with or without infection);
- people who choose not to be tested despite past or current risk behaviour;
- people who are unaware of the risks for HIV involved in specific behaviour in which they have previously, or are currently, engaged;
- people with AIDS or other disease related to their HIV infection;
- people experiencing difficulties with employment, housing, finances, family, etc., as a result of HIV infection;
- the family and friends of people who are infected with HIV;
- health workers and others who come into regular contact with people infected with HIV.

Where can HIV/AIDS counselling be provided?

Both prevention-related and supportive counselling can take place in any setting where there is, or could be, a discussion about HIV and AIDS. These include health care clinics, sexually transmitted disease centres, antenatal and postnatal clinics, family planning clinics, community health centres, schools, churches, and all health outreach facilities. There will inevitably be other possibilities that can be explored and tried.

Who should provide HIV/AIDS counselling?

In addition to doctors, nurses, psychologists, and social workers, other people can readily be encouraged and trained to provide counselling support. Counsellors need not be formal health care providers: teachers, health educators, religious and community leaders, youth group workers, and members of self-help groups can also provide preventive and supportive counselling.

Why is counselling about HIV necessary?

A diagnosis of HIV infection or AIDS, or a suspicion or recognition of the possibility of infection, brings with it profound emotional, social, behavioural, and medical consequences. The subsequent individual and social adjustments required often have implications for family life, sexual and social relations, work, education, spiritual needs, legal status, and civil rights. Adjustment to HIV infection involves constant stress management and adaptation. It is a dynamic, evolutionary, and lifelong process that makes new and changing demands on the infected individuals, their families and the communities in which they live.

Most people are limited in what they can do, or feel they can do, and what changes they can make in their lives. Whether these limitations are real or imagined, they have to be taken into account and dealt with if behaviour modification is to be successful and sustained.

During the course of HIV infection, a broad range of physical needs and problems are likely to be experienced. These are not constant, but will progressively become more serious and difficult to handle. The changing nature of these needs imposes a variety of psychological and emotional strains on infected individuals and those closest to them. These strains may make the infected person feel that he or she is losing identity, independence, privacy, and social status. They can also provoke guilt, anger, and fear of loneliness, dying and death. Dealing with HIV infection also imposes direct and indirect financial costs, which can be particularly stressful if economic productivity is affected by illness; much of the stress experienced by people infected with HIV may reflect underlying anxieties about economic independence and family obligations.

Counselling therefore has to take into account not only the client's immediate social and medical environment, but also his or her social relationships and attitudes and beliefs about HIV/AIDS. Counselling has to provide education and information in a way that is relevant to the day-to-day life of the person concerned. It has to take account of such things as the patient's sexual needs and history, occupation, education, aspirations, and hopes, together with what it will take to inspire a new approach to safer sex and responsible social relationships.

Counselling of the family, lovers, friends, employers, or colleagues of people with HIV infection must provide up-to-date, technically correct information. It should take into account the life-style of the infected person and explore the opportunities for, and constraints on, changes in behaviour and constructive adaptation to HIV infection.

If counselling is to be effective it must be seen by the client as acceptable. Acceptability will be improved if the counselling clearly takes into account the many social relationships, commitments, and obligations that the individual has. Each of these relationships may be a potentially motivating and supporting one.

In summary, counselling people about HIV infection is important because:

- infection with HIV is lifelong;
- a person can avoid acquiring HIV infection or transmitting it to others by changing behaviour;
- awareness of HIV infection can create enormous psychological pressures and anxieties that can delay constructive change or worsen illness, especially in view of the fear, misunderstanding, and discrimination provoked by the HIV epidemic.

3. The main functions of counselling

Prevention

Counselling is concerned with preventing infection with HIV and its transmission to other people. There are five main steps in prevention counselling:

- determine whether the behaviour of an individual or group of individuals involves a high risk of HIV infection;
- work with the people concerned to help them understand and acknowledge the risks associated with their behaviour;
- define with them how their life-style and self-image are linked to this behaviour;
- help individuals define their potential for changing behaviour; and
- work with individuals to introduce and sustain the modified behaviour.

Within any culture or social group, high-risk behaviour is likely to be influenced by a variety of factors. Peer-group pressure to act in a particular way, financial pressure, cultural beliefs about what is acceptable and expected, and lack of knowledge about the risks involved may all play a role, according to the person and situation concerned.

Prevention counselling needs to include a substantial amount of education about health. The health education messages should be made personally relevant, should refer to achievable aims, and need to be presented in the context of detailed and sympathetic discussion. More than anything else, prevention counselling seeks to encourage individuals and groups to make choices about their own life-styles and responsibilities. In order for such counselling to be effective, there has to be consistently accessible support for the individual or group. Where there is no feeling of exchange between the counsellor and the client, and no feeling of genuine support, the essence of the prevention message can often be lost.

Primary prevention

Primary prevention counselling is for people who are at risk of HIV infection but are not known to be infected. Some of them may already recognize that they are at risk; others will be unaware of the risk involved in their behaviour. Primary prevention counselling thus focuses on highlighting and discussing behaviour that presents a risk of HIV infection, and re-

viewing ways of managing individual change according to the steps outlined above. In any society, a variety of individuals and groups may be at risk. Prostitutes (commercial sex workers) and their clients, other men and women with many sex partners, men who have homosexual relationships, people with haemophilia, and people who inject drugs deserve special attention. In addition, military personnel, truck drivers, and migrant workers who spend long periods away from home, and adolescents may feel some pressure to engage in risky behaviour in their everyday circumstances. Each group presents a different challenge with regard to how and where it can be reached. Bars, clubs, hospitals, drug treatment centres, military bases, schools, youth clubs, and sports clubs can all provide opportunities for counselling or at least for informing people about the availability of counselling.

Secondary prevention

For persons known or considered likely to be HIV-infected, counselling should emphasize the implications of HIV infection and the ways in which transmission can be avoided. This should be done in an atmosphere of support and understanding, focusing on the need for infected persons to recognize their responsibility for the health and welfare of those with whom they may have sexual contact.

Referral of HIV-infected people by health centres, testing facilities, hospitals, and other institutions or organizations is especially important. The staff of all of these need to know where counselling is available. They also need to be able to help the client find a counselling service that is physically and socially accessible and likely to be acceptable.

Outreach counselling services for secondary prevention may need to be just as innovative as primary prevention programmes. Some people diagnosed as HIV-infected are likely to move from place to place in search of friends, support, and care and in an effort to deal emotionally with their fear of AIDS. They may be reluctant to participate in counselling or any other follow-up activity unless creative steps are taken to reach them and help them appreciate the benefits of counselling.

In secondary prevention counselling, the question of sexual transmission of HIV needs to be addressed. The importance of adopting practices that eliminate or minimize the possibility of infecting sex partners has to be emphasized. Use of condoms, low-risk sexual practices, alternative ways of seeking gratification, and celibacy will need to be discussed. Similarly, the need to inform current and previous partners about the possibility of their having been infected may need to be considered, and different ways of reaching these people reviewed.[1]

[1] See: *Prevention of sexual transmission of human immunodeficiency virus*. Geneva, World Health Organization, 1990 (WHO AIDS Series 6).

Counselling also needs to stress that the infected person should not donate blood or share syringes, needles, or other skin-piercing equipment. Users of injectable drugs often have or share with friends who share the same behaviour. Pressure from friends to continue high-risk practices is therefore likely and has to be planned for. Similarly, the difficulty of reaching and working with intravenous drug users, who may be afraid of prosecution or rejection by family and acquaintances who do not know about their drug-using behaviour, will have to be addressed.

Perinatal transmission may also be an important concern. In the case of already pregnant women, the question of possible interruption of pregnancy will have to be dealt with, taking into account the many cultural, familial, and medical factors that can influence such a decision. Prevention of future pregnancies should also be discussed.

Psychosocial support

People with diagnosed HIV infection and HIV-related illness, including AIDS, and those close to them are confronted by a multitude of problems, and often need emotional and/or practical support. Anxiety about having spread infection, physical isolation, hospitalization, discrimination within the community or family, loss of housing, interruption of education, financial problems, the physical effects of illness, disease progression, loss of relationships, bereavement, anger, loneliness, and depression are all concerns that may have to be addressed.

These problems may arise intermittently, both for the infected person and for those providing care. The fact that they are not constant and not always predictable produces added physical and emotional stress. Supportive counselling can be particularly helpful in identifying the circumstances in which these concerns are likely to be present and in helping the person plan how best to deal with them. Where this is not possible, supportive counselling can help the person react positively to problems.

It is important to remember that supportive counselling should be a process of empowerment for the person with HIV. Living with HIV infection or disease does not mean living despite HIV; through counselling, the person's own strengths and resources can be mobilized to face and manage such concerns. Some people may be able to cope with their problems without counselling, but for those who cannot, counselling can help them to appreciate aspects of their life that they might otherwise overlook or forget.

Supportive counselling should help those affected by HIV to live full and productive lives by enabling them to resume (or assume) authority over their lives and decision-making. It can often place problems in a new light,

allowing a creative approach to problem-solving and decision-making. Counsellors may often find themselves in the role of "patient advocate", generating a therapeutic strength in individuals, families, or communities by their support.

Enabling people to remain active in their work, in their education, in their families, and among friends helps to reduce their dependence on health and social services and can also reduce the likelihood of psychological problems.

4. Requirements of counselling

Essential features of counselling

Approaches to counselling are likely to vary from one country to another and between social groups. The availability of resources, the conventional or traditional ways in which illness and disease are understood, and the ways in which advice and help are sought and provided will all influence the pattern and techniques of counselling. The characteristics of the person being counselled and his or her social and family networks will also govern the extent to which counselling is needed. Nevertheless, there are a number of features common to all counselling situations.

Time

Providing the client with time is important from the start. Much of the content of counselling, such as helping the person to absorb news about the diagnosis of AIDS, cannot be rushed. The concerns that will be raised, whether the client is HIV-infected or not, are complex and sensitive and need time to be considered and dealt with. Time is also necessary to permit the development of rapport and trust, both of which are indispensable. Some people may require a number of counselling sessions before they start to acknowledge the need to modify their behaviour and to make difficult decisions about their life-style.

Acceptance

People with HIV infection and/or disease, including AIDS, should feel that they are fully accepted by the counsellor, irrespective of their life-style, sexual preference, and socioeconomic, ethnic or religious background. Responses to their needs should be both technically sound and sensitive to their personal circumstances and should not be affected by the counsellor's own feelings.

Accessibility

Counselling should be easy to obtain. People who need counselling should feel that they can ask for a meeting or call on the counsellor at any time. This may require counsellors to be available on a regular basis. It may also mean having to call on other helpers who, with some basic training, can provide additional counselling support. Counselling services must also be seen to be easily accessible; this, in turn, may mean their being based in health or other facilities that are easy to get to, socially accessible, and easy to use.

Consistency and accuracy

Any information provided through counselling (e.g., about HIV infection, risk of infection, and risk reduction) should be consistent. The counsellor therefore needs to have a clear understanding of the facts about HIV infection and disease, and to maintain close and confidential links with other health workers providing care to that person. All persons providing counselling should have access to up-to-date information about HIV infection and its management, so that questions from clients can be answered as accurately as possible. Any uncertainties in knowledge should be acknowledged so that new information can be introduced in a consistent framework.

Confidentiality

Trust is one of the most important factors in the relationship between the counsellor and the person being counselled. Trust improves the working relationship and increases the likelihood that the individual (or the group) will act on the information provided. Given the possibility of discrimination against, and ostracism of, an individual diagnosed as having HIV infection, it is extremely important that confidentiality be guaranteed. The counselling relationship must be built on the understanding that whatever is discussed will remain a private issue until the client decides otherwise.

There may be some instances where the counsellor or other health care worker feels that confidentiality needs to be broken, for example, to notify the sex partners of an infected person when the client has refused permission to do so. The Consensus Statement from the WHO Consultation on Partner Notification for Preventing HIV Transmission[1] specifies that in such situations, the health care provider "will be required to make a decision consistent with medical ethics and relevant legislation". In general, where confidentiality is preventing the adoption of appropriate measures for avoiding the spread of HIV, it may be necessary to reconsider the situation in that particular case.

Counselling activities

The overall duration of counselling has to be governed by the needs of the individual. Similarly, while the content of counselling may vary according to the circumstances, the features described below will always be important.

[1] *Prevention of sexual transmission of human immunodeficiency virus.* Geneva, World Health Organization, 1990 (WHO AIDS Series 6), Annex 2.

Counselling should help clarify and address problems

It is important to determine whether and how the client will be able to manage new information at times of physical or emotional stress: periodic, sensitive appraisal should be made of the person's ability to cope with the latest diagnosis and prognosis. It is equally important to review regularly the effect that the evolving physical illness is having on the individual's ability to cope emotionally and intellectually with day-to-day decisions and actions.

Early and accurate identification of problems can help the patient come to terms with fears and concerns about family affairs. Planning for the family, for example, in the event of chronic illness or death, is important, especially where children are involved.

Counselling should provide information on available resources

As HIV infection progresses, different medical, psychosocial, and welfare needs emerge. Information should be provided on the facilities, self-help groups, community resources, and medical support available, as well as on changes in life-style that can be made to accommodate emerging needs. Promotion of safer sex or avoidance of pregnancy, for example, should be accompanied by information on where to get condoms and other contraceptives.

Counselling should help the client to adopt a realistic approach to changing life-style

Counsellors should help clients to change their life-style only after a review of their family background, including such characteristics as education and financial situation. Counselling should help people select approaches that are feasible and likely to provide the personal satisfaction and support needed to carry through particular behaviour. This may involve introducing the person to groups of people who have themselves been through similar experiences, particularly if they are willing to provide support, for example, peer groups of homosexual, drug-using, or heterosexual people, who are themselves HIV-infected or who are partners of infected people.

Counselling should motivate and facilitate decision-making

People are more motivated to change when they feel they have control over their lives and their decisions, and when their life-skills, self-respect, and confidence are increased. It is important to encourage positive steps taken

and attempts made, and to offer a sympathetic but realistic appraisal of why they are or are not working according to expectations. Maintaining status within the community is equally likely to be a source of motivation. Explaining that particular actions will help loved ones may be a critical source of motivation.

5. Counselling before HIV testing or screening

Undergoing a test for HIV infection is likely to be an important step in a person's life, and should always be accompanied by pre-test and post-test counselling.

The aim of pre-test counselling

Counselling before the test should provide individuals who are considering being tested with information on the technical aspects of screening and the possible personal, medical, social, psychological, and legal implications of being diagnosed as either HIV-positive or HIV-negative. The information should be given in a manner that is easy to understand and should be up to date. Testing should be discussed as a positive act that is linked to changes in risk behaviour.

A decision to be tested should be an informed decision. Informed consent implies awareness of the possible implications of a test result. In some countries, the law requires explicit informed consent before testing can take place; in others, implicit consent is assumed whenever people seek health care. There must be a clear understanding of the policy on consent in every instance, and anyone considering being tested should understand the limits and potential consequences of testing.

Testing for HIV infection should be organized in a way that minimizes the possibility of disclosure of information or of discrimination. In screening, the rights of the individual must also be recognized and respected. Counselling should actively endorse and encourage those rights, both for those being tested and for those with access to the records and results. Confidentiality should be ensured in every instance.

Issues in pre-test counselling

Pre-test counselling should focus on two main topics: first, the client's personal history and risk of being or having been exposed to HIV; secondly, assessment of the client's understanding of HIV/AIDS and previous experience in dealing with crisis situations.

Assessment of risk

In assessing the likelihood that the person has been exposed to HIV, the following aspects of his or her life since about 1980 should be taken into account:

- Frequency and type of sexual behaviour; specific sexual practices, in particular, high-risk practices such as vaginal and anal intercourse without use of condoms, unprotected sexual relations with prostitutes.
- Being part of a group with known high prevalence of HIV infection or with known high-risk life-styles, for example, users of intravenous drugs, male and female prostitutes and their clients, prisoners, and homosexual and bisexual men.
- Having received a blood transfusion, organ transplant, or blood or body products.
- Having been exposed to possibly nonsterile invasive procedures, such as tattooing and scarification.

Assessment of psychosocial factors and knowledge

The following questions should be asked in assessing the need for HIV testing:

- Why is the test being requested?
- What particular behaviour or symptoms are of concern to the client?
- What does the client know about the test and its uses?
- Has the client considered what to do or how he/she would react if the result is positive, or if it is negative?
- What are the client's beliefs and knowledge about HIV transmission and its relationship to risk behaviour?
- Who could provide (and is currently providing) emotional and social support (family, friends, others)?
- Has the client sought testing before and, if so, when, from whom, for what reason, and with what result?

The initial counselling should include a discussion and assessment of the client's understanding of (*a*) the meaning and potential consequences of a positive or a negative result, and (*b*) how a change in behaviour can reduce the likelihood of infection or transmission to others.

Pre-test counselling should include a careful consideration of the person's ability to cope with the diagnosis and the changes that may need to be made in response to it. It should also encourage the person being counselled to consider why he or she wishes to be tested and what purpose the test will serve. When asking about personal history, it is important to remember that the client:

- may be too anxious to absorb fully what the counsellor says;
- may have unrealistic expectations about the test; and
- may not realize why questions are being asked about private behaviour and therefore be reluctant to answer.

During pre-test counselling, it is also important that the client be told that current testing procedures are not infallible. Both false-positive and false-negative results occur occasionally, although supplementary (confirmatory) tests are very reliable if an initial test is positive. These facts must be clearly explained, together with information about the "window" period during which the test may be unable to assess the true infection status of the person (see page 3).

If testing is not available

There may be locations where reliable facilities for testing are not readily available. Where this is so, every effort should be made to emphasize prevention counselling, especially the need for changes in behaviour among people who have engaged in high-risk activities, and the reinforcement of appropriate behavioural changes. Counselling, education, information, and support are the crux of behaviour change.

Once a person has decided to be tested for HIV antibodies, arrangements should be made for post-test counselling.

6. Counselling after HIV testing or screening

Counselling after testing will depend on the outcome of the test, which may be a negative result, a positive result, or an equivocal result.

Counselling after a negative result

It is very important to discuss carefully the meaning of a negative result (whether this was anticipated or not). The news of being uninfected is likely to produce a feeling of relief or euphoria, but the following points should be emphasized:

- Following possible exposure to HIV, there is a "window" period during which a negative test result cannot be considered reliable. This means that, in most cases, at least three months must have elapsed from the time of possible exposure before a negative test can be considered to mean that infection did not occur. A negative test result carries greatest certainty if at least six months have elapsed since the last possible exposure.

- Further exposure to HIV infection can be prevented only by avoiding high-risk behaviour. Safer sex and avoidance of needle-sharing must be fully explained in a way that is understood and permits appropriate choices to be made.

- Other information on control and avoidance of HIV infection, including the development of positive health behaviour, should be provided. It may be necessary to repeat explanations and for the counsellor and the person being counselled to practise methods of negotiating with others in order to assist the client in introducing and maintaining new behaviour.

Counselling after a positive result

People diagnosed as having HIV infection or disease should be told as soon as possible. The first discussion should be private and confidential, and then the client should be given time to absorb the news. After a period of preliminary adjustment, the client should be given a clear, factual explanation of what the news means. This is *not* a time for speculation about prognosis or estimates of time left to live. It is a time for acknowl-

edging the shock of the diagnosis and for offering and providing support. It is also a time for encouraging hope—hope for achievable solutions to the personal and practical problems that may result. Where resources are available, it may also be justifiable to talk of possible treatments for some symptoms of HIV infection and about the efficacy of antiviral treatments. Important practical information for people with HIV infection is presented in Annex 3.

How the news of HIV infection is accepted or incorporated often depends on the following:

1. The person's physical health at the time. People who are ill may have a delayed reaction. Their true response may appear only when they have grown physically stronger.

2. How well prepared the person was for the news. People who are completely unprepared may react very differently from those who were prepared and perhaps expecting the result. However, even those who are well prepared may experience the reactions described in the following pages.

3. How well supported the person is in the community and how easily he or she can call on friends. Factors such as job satisfaction, family life and cohesion, and opportunities for recreation and sexual contact may all make a difference in the way a person responds. The reaction to the news of HIV infection may be much worse in people who are socially isolated and have little money, poor work prospects, little family support, and inadequate housing.

4. The person's pre-test personality and psychological condition. Where psychological distress existed before the test result was known, the reactions may be either more or less complicated and require different management strategies than those found in persons without such difficulties. Post-result management should take account of the person's psychological and/or psychiatric history, particularly as the stress of living with HIV may act as a catalyst for the reappearance of earlier disturbance.

   In some cases, news of infection can bring out previously unresolved fears and problems. These can often complicate the process of acceptance and adjustment and will need to be handled sensitively, carefully, and as soon as possible.

5. The cultural and spiritual values attached to AIDS, illness, and death. In some communities with a strong belief in life after death, or with a fatalistic attitude towards life, personal knowledge of HIV infection may be received more calmly than in others. On the other hand, there may be communities in which AIDS is seen as evidence of antisocial or blasphemous behaviour and is thus associated with feelings of guilt and rejection.

Counselling and support are most needed when reactions to the news of HIV infection or disease appear. Some reactions may initially be very intense. It is important to remember that such responses are usually a normal reaction to life-threatening news and as such should be anticipated.

Psychological issues

The psychological issues faced by most people with HIV infection or disease revolve around uncertainty and adjustment.

With HIV infection, uncertainty emerges with regard to hopes and expectations about life in general, but it may focus on family and job. An even more fundamental uncertainty may concern the quality and length of life, the effect of treatment, and the response of society. All these are relatively unpredictable in terms of their long-term outcome. They need to be discussed openly and frankly, but care should always be taken to encourage hope and a positive outlook.

In response to uncertainty, the person with HIV must make a variety of adjustments. Even the apparent absence of a response may, in itself, be an adjustment through denial (see below). People start to adjust to news of their infection or disease from the time they are first told. Their day-to-day lives will reflect the tension between uncertainty and adjustment. It is this tension that causes other psychosocial issues to assume more or less prominence and intensity from time to time.

Fear

People with HIV infection or disease have many fears. The fear of dying and, particularly, of dying alone and in pain is often very evident. Fear may be based on the experiences of loved ones, friends, or colleagues who have been ill with, or died of, AIDS. It may also be due to not knowing enough about what is involved and how the problems can be handled. As with most psychological concerns, fear and the pressures such fear creates can often be managed by bringing them clearly and sensitively into the open. They should be discussed in the context of managing the difficulties, including with the help of friends and family or with the counsellor.

Loss

People with HIV disease experience feelings of loss about their lives and ambitions, their physical attractiveness and potency, sexual relationships, status in the community, financial stability, and independence. As the need for care increases, a sense of loss of privacy and control over life will also be experienced. Perhaps the most common loss that is felt is the loss of confidence. Confidence can be undermined by many aspects of life with HIV, including fear for the future, anxiety about the coping abilities of loved ones and care-givers, by the negative and/or stigmatizing actions of others. For many people, recognition of HIV infection will be the first

occasion that forces them to acknowledge their own mortality and physical vulnerability.

Grief

People with HIV infection often have profound feelings of grief about the losses they have experienced or are anticipating. They may also suffer the grief that is projected on to them by close family members, lovers, and friends. Often these same people are supporting and taking care of them on a day-to-day basis, and watching their health decline.

Guilt

A diagnosis of HIV infection often provokes a feeling of guilt over the possibility of having infected others, or over the behaviour that may have resulted in the infection. There is also guilt about the sadness the illness will cause loved ones and families, especially children. Previous events that may have caused pain or sadness to others and remained unresolved will often be remembered at this time and may cause even greater feelings of guilt.

Depression

Depression may arise for a number of reasons. The absence of a cure and the resulting feeling of powerlessness, the loss of personal control that may be associated with frequent medical examinations, and the knowledge that a virus has taken over one's body are all important factors. Similarly, knowing others or about others who have died or are ill with HIV disease, and experiencing such things as the loss of potential for procreating and for long-term planning may contribute to depression.

Denial

Some people may respond to news of their infection or disease by denying it. For some people, initial denial can be a constructive way of handling the shock of diagnosis. However, if it persists, denial can become counter-productive, since people may refuse to accept the social responsibilities that go with being HIV-positive.

Anxiety

Anxiety can quickly become a fixture in the life of the person with HIV, reflecting the chronic uncertainty associated with the infection. Many of the reasons for anxiety reflect the issues discussed above and concern the following:

- prognosis in the short and long term;
- risk of infection with other diseases;

- risk of infecting others with HIV;
- social, occupational, domestic, and sexual hostility and rejection;
- abandonment, isolation, and physical pain;
- fear of dying in pain or without dignity;
- inability to alter circumstances and consequences of HIV infection;
- how to ensure the best possible health in the future;
- ability of loved ones and family to cope;
- availability of appropriate medical/dental treatment;
- loss of privacy and concern over confidentiality;
- future social and sexual unacceptability;
- declining ability to function efficiently;
- loss of physical and financial independence.

Anger

Some people become outwardly angry because they feel they have been unlucky to catch the infection. They often feel that they, or information about them, has been badly or insensitively managed. Anger can sometimes be directed inwardly in the form of self-blame for acquiring HIV, or in the form of self-destructive (suicidal) behaviour.

Suicidal activity or thinking

People who are HIV-infected have a significantly increased risk of suicide. Suicide may be seen as a way of avoiding pain and discomfort or of lessening the shame and grief of loved ones. Suicide may be active (i.e., deliberate self-injury resulting in death) or passive (i.e., concealing or disregarding the onset of a possibly fatal complication of HIV infection or disease).

Self-esteem

Self-esteem is often threatened early in the process of living with HIV. Rejection by colleagues, acquaintances, and loved ones can quickly lead to loss of confidence and social identity, and thus to reduced feelings of self-worth. This can be compounded by the physical impact of HIV-related diseases that cause, for example, facial disfigurement, physical wasting, and loss of strength or bodily control.

Hypochondria and obsessive states

Preoccupation with health and even the smallest physical changes or sensations can result in hypochondria. This may be transient and limited to the time immediately after diagnosis, or it may persist in people who find difficulty in adjusting to the disease.

Spiritual concerns

Concern about impending death, loneliness, and loss of control may give rise to an interest in spiritual matters and a search for religious support. Expressions of sin, guilt, forgiveness, reconciliation, and acceptance may appear in the context of religious and spiritual discussions.

Many of these and other concerns will appear or become pronounced when a diagnosis of AIDS is made. The appearance of new infections, cancers, and periods of severe fatigue all have a significant emotional and psychological impact. The effect is likely to be even greater if the person with AIDS has been rejected by family or friends and has withdrawn from normal social relationships.

Other counselling issues

HIV infection often highlights other issues critical to quality of life.

Social issues

Environmental and social pressures, such as loss of income, discrimination, social stigma (if the diagnosis becomes commonly known), relationship changes, and changing requirements for sexual expression, may contribute to post-diagnosis psychosocial problems. The patient's perception of the level and adequacy of social support is of vital concern and may become a source of pressure or frustration.

Medical management

The type of counselling support usually required and requested is often influenced by the person's experiences with other forms of health care related to the infection. Where the patient or loved ones feel that medical management has been insensitive or has been conducted without sufficient regard for privacy, counselling may be all the more necessary in order to persuade the patient to comply with recommended treatment programmes.

Counselling may also involve helping the person gain access to appropriate medical care and participate more fully in decisions about treatment. If there is any evidence of neurological disease, day-to-day management of the patient may be complicated, and special emphasis will have to be given to counselling of family, loved ones, and care-givers.

At this stage, counsellors may need to coordinate a range of health and social services. Many people with HIV will also seek care from traditional or complementary healers; this may first be revealed in the context of supportive counselling. Where this is the case, counselling can help patients talk about their perceived needs and their satisfaction with these care-givers.

Counselling after an equivocal test result

If the result of the HIV test is equivocal, the counsellor has particular responsibilities to provide information. In particular, there are two main issues to cover:

1. The person should be given a clear explanation of what such a test result means. The first test most commonly used on all samples is the enzyme-linked immunosorbent assay (ELISA). The ELISA has levels of sensitivity and specificity approaching 99.5%, meaning that a non-reactive result with this technique can be regarded as a definite indicator that the person is not infected, except for tests during the "window period". However, a reactive result suggests the possibility of HIV infection. The usual procedure in that case is to perform a second test using the ELISA; if the second ELISA test is also positive, supplementary testing is required, for example using the Western blot test. The results of such supplementary testing may be positive (indicating HIV infection), negative (indicating no infection), or indeterminate (giving an equivocal result). Where the result of supplementary testing is indeterminate (which may be the case in up to 10% of samples in some areas), the reason may be one of the following:

   - the test is cross-reacting with a non-HIV protein (usually, the protein reaction is simulating the reaction associated with p24 core protein).
   - there has been insufficient time for full seroconversion to occur since the person was exposed to HIV.

   When presented with an indeterminate result, the options are to:

   - Use other methods to try to achieve a reliable result. Combinations of laboratory techniques may be needed to exclude false-positive results.
   - Not carry out further testing for the moment. If the result is indeterminate and further testing is not possible, the person cannot reliably be considered HIV-infected. The counsellor should advise the person to come for repeat testing in three months. It is important to remember that the risk of finding a false-positive

result in the ELISA is higher in areas with a low level of HIV infection than where background rates of HIV infection are high. Thus, in places where there are many people with AIDS in the community, it is more likely that a reactive or positive result in the ELISA is accurate.

2. Prevention and support while waiting for an unequivocal result. The period of uncertainty following an equivocal test result may be three months or longer. It is important for counsellors to stress essential messages related to prevention of transmission, regarding sexual activity, drug use, donation of body fluids or tissues, and breast-feeding (see p. 37). Just as importantly, however, the uncertainties associated with this period may lead to acute and severe psychosocial difficulties (see pp. 27–31), and the counsellor must be prepared to assess and manage such issues or to make appropriate referrals, if possible.

Self-help groups

In some places the counsellor can call on peer-support or self-help groups, part of a growing network of nongovernmental AIDS service organizations (ASOs). These can provide a type of personal care and peer-based psychosocial support that may not be available elsewhere. If no such groups exist, the counsellor may be able to encourage clients to form one. Where this is not possible, the counsellor may be able to put clients in touch with each other on an individual basis, at the discretion of the counsellor and with the express consent of the individuals and on a confidential basis. Matters that are often best dealt with through self-help groups, but which need to be raised by the counsellor in any event, include the following:

1. Learning to live with HIV infection. Self-help groups are often in a good position to address this because many of the people involved may have already gone through the process. They can describe the medical and psychological problems they have experienced and the interventions they have found most useful.

2. Helping care-givers and loved ones handle the pressures of living with sick or distressed people on a daily basis, especially where this involves managing bleeding, vomiting, incontinence, disposal of dressings, etc., and advice regarding sexual relations.

3. Reducing stress and avoiding conflict. The need to overcome anxiety, depression and other possible challenges to sustained health has to be handled on a practical, "I did this ..." basis.

4. Deciding how best to talk about HIV/AIDS. Fears of disclosing a diagnosis of HIV or AIDS to loved ones, family, friends, and

colleagues need to be examined and solutions sought, including what to say, to whom, when, and how.

5. Dealing with feelings of loneliness, depression, and powerlessness. Self-help or peer-support groups can provide help and mutual support. Advice from people who have themselves gone through such feelings may be more meaningful than advice provided on a second-hand or theoretical basis.

6. Managing the implications of adopting and maintaining safer sex behaviour. Peer-support groups can organize discussions and training that can be far more relevant than advice provided through formal health care programmes. Peer commitment to safer sex also helps make these practices socially acceptable, attractive and thus sustainable.

The essence of peer-support group activity is a feeling of group cohesion, a sharing of experiences and mutually supportive activities. At times, such groups may need help in getting started and in maintaining regular activities. They will all look to the counsellor for help in identifying medical services and care-givers. Providing legal advice and, in some cases, financial support may also become issues in establishing such groups and giving them operational legitimacy.

7. Needs of significant others

The term "significant others", as used here, refers to people who are closely involved with an HIV-infected individual. Significant others are critical because of the influence they may have on the health and well-being of the infected person. They are also themselves at risk of psychosocial stress because of their emotional involvement with the infected person.

Health workers

Health workers who deal with HIV-infected persons or those with HIV-related diseases on a day-to-day basis often suffer psychosocial distress. Emotional involvement with the patient and frustration at the lack of effective therapy can place health workers at risk of depression, withdrawal and, in extreme cases, suicidal tendencies.

Counselling of health workers should be an integral part of all health care programmes where the prevalence of HIV infection is high. Counselling should seek to minimize stress and may need to include helping set work schedules that provide frequent changes of environment and tasks. Just as for those who are HIV-infected, counselling for health workers should be accessible, consistent, and confidential.

The family

For many HIV-infected people, including those with HIV-related disease, families are the main source of care and support. The type of care required will depend on the stage of infection: as the patient's condition deteriorates, so the demands on the family increase. The time and energy required and the emotional involvement will increase and draw the family away from other activities and responsibilities.

At the same time, the family may experience the same fears (e.g., of ostracism and recrimination) as the infected person. Counselling of family members may be increasingly needed as infection progresses addressing both the needs of the family as a unit and as individuals. This is all the more important in situations where AIDS has generated fear and rejection.

Families are also likely to need technical support. It may be necessary to provide them with medications, disinfectants, and information on the course of infection and possible treatment. Regular visits by health workers, as well as the counsellor, may be an important form of support. The financial needs of the family also have to be considered; the role of the community and national social security systems will have to be explored.

Most importantly, the concept of family should be flexible and include families of choice as well as of birth or marriage. Some people have surrogate families that provide the emotional and practical support usually associated with the more conventional notions of family.

8. Some special issues

Pregnancy

Women of childbearing age who are known to be infected should be counselled as early as possible to permit them to make an informed decision regarding becoming pregnant or postponing or avoiding pregnancy. It will be important for the counsellor to explain that HIV can be transmitted from an infected woman to her fetus during pregnancy or to the infant during birth or possibly through breast-feeding. At present, the risk of transmission is estimated to be between 20% and 40%. The prognosis for the pregnant woman with HIV infection, in terms of disease progression, is uncertain but it may be appropriate to consider this issue together with the issue of fostering surviving children.

Sometimes the pressure on women to bear children and/or their desire to do so may make the decision to avoid pregnancy a difficult one. A decision should not be imposed, but women should be told very clearly about the risks and supported in making their choice. If contraception is desired, the counsellor should ensure that couples are provided with information, advice, and supplies of safe, effective, and acceptable contraceptives. The counsellor should help them obtain expert instruction and follow-up with regard to their choice and use of contraceptives.

When HIV infection occurs during pregnancy or when an HIV-infected woman becomes pregnant, the woman will need special counselling and medical attention. Counselling on possible courses of action during pregnancy is generally limited to sensitive support and careful discussion of possible outcomes. Whether termination of pregnancy is mentioned will depend on local and personal religious and cultural factors, the national law on abortion, the stage of gestation, and existence of local facilities for safe termination of pregnancy. The pregnant woman should be prepared for the possibility that the child will be born with HIV infection, but also assured that she has at least a 60% chance of having an uninfected infant.

The husbands or sex partners of HIV-infected women who are planning to become pregnant or are already pregnant should be included in counselling sessions. Where possible, decisions about avoiding or terminating a pregnancy or about preparing for a possibly infected infant should involve both potential parents. The social and psychological support the woman will need is likely to be best assured with the cooperation of her partner.

Infants with suspected HIV infection

As indicated above, the chances of an HIV-infected pregnant woman's giving birth to an infected infant are between 20% and 40%. Infants born

to infected mothers, whether or not they themselves are infected, carry passive maternal antibodies; they will therefore be positive on HIV serological testing. In most cases, such passive antibodies disappear by nine months of age, but they may persist for 18 months. During this time, it is impossible to tell by serological testing alone whether the child is infected. However, infants may begin to show signs of HIV-related disease well before an unequivocal test result can be obtained.

The infant should be kept under medical observation, but otherwise should be treated normally, being given as much care and affection as possible. Psychosocial support, emotional stimulation and adequate nutrition should be ensured. Parents and siblings may need counselling, and if possible, the counsellor should put the parents in touch with a local self-help parents' group.

Although the virus may be present in the infant's body fluids, there is virtually no risk of HIV being transmitted to other family members in the home. Nevertheless, people with cuts or abrasions should avoid contact with these fluids. Part of the counsellor's role may be to teach or reinforce conventional hygienic practices and to see that family members have such materials as disinfectant and soap.

Breast-feeding

Most transmission of HIV from mother to offspring occurs during pregnancy and possibly during delivery. The additional risk of transmitting HIV to the infant through breast-feeding is low. However, if a mother first becomes infected during lactation, e.g., through an infected blood transfusion postpartum, there is a significant risk of transmitting HIV infection to the infant via breast milk. Similarly, women who have symptoms of AIDS may be more likely to infect their infants via breast milk.

It should be borne in mind that breast milk is crucial to the health and well-being of most infants. From a nutritional, immunological and psychosocial perspective, breast milk is ideally suited to the needs of the neonate and young infant. The psychosocial and health benefits of breast-feeding for mothers are also well documented. Infants who are not breast-fed are more vulnerable to diarrhoeal, respiratory, and other infectious diseases, all of which may be life-threatening. Where the infant is HIV-infected, breast milk from an infected mother may protect the infant from infections that could accelerate progression to overt HIV-related disease.

In many situations the safe and effective use of breast-milk substitutes cannot be guaranteed because of lack of clean water, difficulties with sterilizatioa of feeding equipment, and lack of money to buy these foods in adequate amounts. In such circumstances breast-feeding by the mother should continue to be the feeding method of choice, irrespective of her HIV status.

Children in school

HIV is not transmitted by normal social contact, and HIV-infected schoolchildren do not pose a risk for other schoolchildren. Where an infected schoolchild has haemophilia, the haemophilia condition should be known to the school health service as well as to the child's teachers. They may not know about the HIV infection, however, and the counsellor must not divulge that information. If they already know, the counsellor will be free to discuss potential problems, such as the possibility of social stigma, with the child's doctor or school medical officer and, where necessary, with the school staff.

Children who know that a schoolmate is infected with HIV may need counselling. The counsellor should take great care to ensure that the information they receive and the language used are appropriate for their age. They should be told that they are not at risk of getting the infection and that they should treat the infected child as they would any other member of their group. Especially, the counsellor should not dramatize the matter or give it any prominence over and above any special attention the child may otherwise be receiving.

HIV-infected children with haemophilia

Particular counselling approaches and techniques have been developed for children with haemophilia, some of which have been adapted for use in counselling HIV-infected children with haemophilia. The counsellor should make it clear to the parents that it is their responsibility to inform a child who can understand such information about the condition and what it means (e.g., why the child is coming for counselling). As a general rule, the child should be included in interviews with the parents and, where appropriate, with grandparents and siblings. The counsellor can then observe the reactions of both the child and other family members. The counsellor should not discuss such issues as sexuality without parental permission. Older children can be seen either alone or with the family, as the children prefer. When family members hear one another's views they may find it easier to make the necessary adjustments for supporting the child and at the same time protecting themselves from any risk of infection. If the child is seriously ill or dying, the parents may need to see the counsellor alone.

Counselling sessions should generally not be long. The counsellor should help the parents in giving explanations to the child or adolescent. Information and knowledge may be the only protection against discrimination at school. Role-playing techniques can be useful with the children and parents to enable them to ask the questions that they consider important. For example, a parent can play the role of a teacher who needs or wants to know about a child in the school with HIV infection.

The counsellor should make use of what is said and done in the interview and use the child's or family's own words to form the next sentence. It is also important to promote the child's self-esteem and self-image and emphasize how well he or she is coping.

The workplace

Exclusion from the workplace can be highly stressful to the HIV-infected person. It can precipitate anxiety about financial stability and about possible breaks in a set of significant social relationships. Employers and/or work associates who come into regular contact with HIV-infected persons need to be counselled on their own situation and protection from infection, as well as on the role they can play in ensuring the integration of those who are infected.

Annex 1

Instructions for condom users

For maximum protection against HIV infection, condoms must be used correctly. Make sure that you understand and follow these instructions:

- Use a new condom every time you have intercourse.
- Always put the condom on the penis before intercourse begins.
- Put the condom on when the penis is erect.
- In putting on the condom, squeeze the nipple or empty space at the end of the condom in order to remove the air. Do not pull the condom tightly against the tip of the penis; leave the small empty space (one or two centimetres) at the end of the condom to hold the semen.
- Unroll the condom all the way to the base of the penis.
- If the condom tears during intercourse, withdraw the penis immediately and put on a new condom.
- After ejaculation, withdraw the penis while it is still erect. Hold the rim of the condom as you withdraw, so that the condom does not slip off.
- Remove the condom carefully so that seminal fluid does not spill out. Dispose of used condoms in a closed receptacle for waste.
- If a lubricant is desired, use a water-based one, since petroleum jelly may damage condoms.
- Do not use saliva as a lubricant—it is ineffective and may lead to breaking of the condom.
- Store condoms away from excessive heat, light, and moisture, as these cause them to deteriorate and perhaps break.
- Condoms that are sticky or brittle or otherwise damaged should not be used.

These written instructions may prove difficult to follow by even the well educated. It is preferable that counsellors become conversant with them and explain them in simple language. Use of simple graphic material is recommended. Consider adapting the culturally appropriate graphics already in use by family planning associations in your area.

Annex 2

Guidelines on prevention of sexual transmission of HIV[1]

The following general guidelines are aimed at individuals or groups. They may need to be adapted to different local situations.

Recommendations to all persons to prevent sexual transmission of HIV

- Be aware that if you have a mutually faithful relationship with your sexual partner, if you are both HIV seronegative, and if neither of you is exposed to contaminated blood, e.g. by using intravenous drugs or sharing needles, you are not at any risk of a sexually transmitted HIV infection.

- If you intend to have sexual intercourse and are not in a mutually faithful sexual relationship, be aware that your chance of acquiring HIV infection is influenced by the following three main factors.

  1. The choice of your sexual partner(s)

     The risk of infection is directly related to the likelihood that your partner may be infected; for heterosexual and homosexual partners, this varies considerably according to the part of the world. Therefore:

     - Do not have sexual relations with casual or unknown partners.
     - Do not have sexual relations with people who may use or have used injectable drugs, such as heroin or cocaine.
     - Do not have sexual relations with people who have many different sexual partners, such as male or female prostitutes.

[1] Taken from: *Prevention of sexual transmission of human immunodeficiency virus.* Geneva, World Health Organization, 1990 (WHO AIDS Series 6).

2. The number of sexual partners

   The greater the number of partners with whom you have sexual intercourse, the greater the likelihood that you will encounter a partner with HIV infection. Therefore reduce the number of sexual partners to the greatest extent possible.

3. The type of sexual behaviour practised

   If you are considering sexual relations with someone whose infection status or sexual or intravenous drug-using history is unknown to you, abstention from sexual intercourse or rigorous restriction of sexual contact to activities that do not involve the sharing of semen, vaginal and cervical secretions, or blood (e.g., hugging, caressing) will eliminate the risk of acquiring HIV infection. In all other instances, the routine correct use of a condom is strongly recommended.

Recommendations to HIV-infected persons

- Inform former and current sexual partners about your HIV infection and recommend that they visit a testing centre or health care provider for counselling and evaluation (including, if available, serological testing). If you are unable or unwilling to notify former and current sexual partners personally, request health workers or public health agencies to notify or help with notifying such partners.

- Inform potential sexual partners of your HIV infection and either decide to avoid sexual intercourse, rigorously restricting sexual contact to activities (e.g., hugging, caressing) that do not involve sharing of semen, vaginal and cervical secretions, or blood, or discuss the precautions that need to be taken to minimize the risk of HIV transmission from sexual activity (e.g., the use of condoms).

- If you both decide to engage in penetrative sexual intercourse, learn how to use a condom correctly, as consistent correct use will reduce the risk of HIV transmission.

- Strictly avoid sexual intercourse when you or your sexual partner has an infection or lesion in the genital, anal, or oral areas and during menstruation.

- Avoid pregnancy. HIV-infected women who are pregnant should know about the health hazard to their unborn child and the potential health hazard to themselves, and be provided with counselling services. HIV-infected men should discuss the hazards of pregnancy with their partners.

- Do not donate blood, plasma, semen, breast milk, body organs, or other tissues.

Recommendations to sexual partners of known HIV-infected persons

- Contact a health care provider for counselling and evaluation (including, if available, serological testing). If the HIV serological test is negative and you are clinically healthy, and if the last unprotected sexual or needle-sharing exposure to your infected partner was six or more months ago, it can generally be assumed that you have not acquired HIV infection from that exposure. If your last exposure was less than six months ago, or if you continue to have sexual intercourse with your infected partner, repeat tests will be necessary to determine whether infection has occurred. If you were negative on initial serological testing, see the recommendations below.

- Be aware that avoiding sexual intercourse with an HIV-infected person or rigorously restricting sexual contact to activities that do not involve sharing of semen, vaginal and cervical secretions, or blood (e.g., hugging, caressing) is the only way of eliminating the risk of acquiring HIV infection from that person. If this is not acceptable, the use of a condom is an alternative, but it is not without risk. Although the precise effectiveness of condoms in preventing HIV infection is unknown, their correct and consistent use will reduce the risk of transmission.

- Avoid all sexual intercourse when either you or your sexual partner has an infection or lesion in the genital, anal, or oral area, and during menstruation.

- If you are pregnant, find out and seek counselling about HIV antibody testing. If you are tested and found to be seropositive, find out and seek counselling about the great health risk to your unborn child and the potential risk to yourself.

- Do not donate blood, plasma, semen, breast milk, body organs, or other tissues.

Recommendations to health care providers

- Be aware of and sensitive to sexual behaviour that places people at risk of HIV infection.

- Obtain a sexual history routinely. Be non-judgemental.

- Educate patients about HIV transmission and its prevention, including as appropriate the avoidance of partners at high risk of infection (e.g., users of intravenous drugs, prostitutes, men who have sex with prostitutes, people who engage in high-risk sexual activities), and provide instruction on the correct use of condoms.

- Offer HIV testing and counselling to people at increased risk of HIV infection.

- Find out what services and resources are available within the community so that people can be referred appropriately.

- Where resources and programmes exist, be prepared to provide additional support through counselling, peer groups, and other services for HIV-infected persons and their sexual partners, or at least refer them to public health or other medical facilities for such support.

- Urge the patient (the index person) to refer sexual contacts, and be prepared to fulfil your role in such referrals, including referring the contacts to public health agencies when indicated.

- Assist HIV-infected and non-infected users of intravenous drugs to obtain treatment for their addiction and to avoid sharing needles and drug-injecting equipment.

- Inform HIV-infected women who are pregnant about the great health risk to their unborn child and the potential risk to themselves, and provide them with opportunities for counselling. Provide similar information and counselling to all HIV-infected women in the child-bearing age group.

Annex 3

Practical information for people with HIV infection or disease

Both support and information on preventing transmission are needed in the post-test or post-diagnosis phase. In addition to dealing with the psychological issues that appear at this time, particularly in people who are HIV-infected, the counsellor should emphasize the information on prevention that will provide the framework for living with HIV. Equally, the following points should be covered in all counselling sessions, both for people who are HIV-positive and those who are HIV-negative:

1. HIV infection is not the same as AIDS. People with AIDS have HIV infection, but only a proportion of those with HIV infection have AIDS.

2. Sexual intercourse, whether heterosexual or homosexual, is the major route of transmission of HIV. The virus can be transmitted by any penetrative sexual act in which HIV-infected semen, vaginal/cervical secretions, or blood is exchanged. Sexual transmission of HIV infection can be prevented: during sexual intercourse, men should always use a condom, each time, from start to finish. Women should be sure that their partners use a new condom for each act of sexual intercourse. Guidelines on preventing sexual transmission are presented in Annex 2, and instructions on how to use a condom are presented in Annex 1.

3. When carefully and consistently used, condoms offer effective protection against transmission of HIV. Latex condoms lubricated with silicone or a water-based lubricant are recommended. When additional lubrication is desired to reduce the risk of condom breakage, a water-based, not oil-based, lubricant should be used. Animal membrane (e.g., lambskin) condoms are believed to be less effective than latex condoms as a barrier against HIV and are therefore not recommended.

4. Non-barrier contraceptives, such as the intrauterine device (IUD), have no protective effect against HIV transmission. It is not clear whether oral and injectable contraceptives affect the risk of HIV transmission. Coordination between AIDS control programmes and family planning services is clearly essential.

5. Certain health conditions, especially other sexually transmitted diseases, may accelerate the progression of HIV infection to AIDS.

Guidelines for avoiding sexually transmitted diseases should be followed by people with HIV as well as those without HIV (see Annex 2). Such guidelines must be clearly explained to both the client and, if possible and with the explicit agreement of the client, his or her sex partner.

6. It is not yet clear whether pregnancy accelerates the progression of HIV infection to AIDS. The uncertainties about this issue must be carefully explained to infected women of childbearing age. The risk of transmission of HIV to the fetus is 20–40%. If HIV-infected women want to avoid pregnancy, they and their sex partners should be given advice about contraceptives. Access to safe and reliable contraceptive methods must be ensured.

7. With regard to immunization, studies have demonstrated that the following vaccines can be safely given to children suspected of being infected with HIV-1: BCG, diphtheria-pertussis-tetanus, poliovirus (oral and inactivated), measles, and tetanus toxoid. However, BCG should not be given if the child has symptoms of HIV-related disease. The safety of other live vaccines, such as yellow fever vaccine, has not been evaluated. In general, where there is a high prevalence of HIV infection, asymptomatic persons should continue to be immunized in accordance with the standard schedules used in the WHO Expanded Programme on Immunization.[1] Immunization is important in protecting HIV-1-infected children, particularly against measles and complications of tuberculosis.[2]

8. Persons with HIV infection and those who are engaged in risk behaviour should never donate body fluids, such as blood, semen, and breast milk, or body organs.

9. If blood from a person infected with HIV is spilt in the home or workplace, it should be soaked up with an absorbent material, such as a cloth, rag, paper towel, or sawdust, direct skin contact with the blood being avoided. The blood-soaked absorbent material should, if possible, be placed in a plastic bag, and then burned in an incinerator or buried. The area that was contaminated with the blood should be washed with a disinfectant—preferably sodium hypochlorite (household bleach) diluted 1:10 with water, to give 0.1–0.5% available chlorine—to clean up any remaining blood. Rubber household gloves should be worn, if available, when spilt blood is being cleaned up. If gloves are not available, another barrier such as a large wad of paper towels should be used to protect against direct skin contact with the blood. Hands should always be washed with soap and water after cleaning up blood or other body fluids.

[1] *Weekly epidemiological record*, **62** (40): 297-299 (1987).
[2] *Weekly epidemiological record*, **64** (7): 48-49 (1989).

Clothes or cloths that are visibly contaminated with blood should be handled as little as possible. Rubber household gloves should be worn, if available, and the clothes or cloths should be placed and transported in leakproof bags. Such items should be washed with detergent and hot water (at least 70°C (160°F)) for 25 minutes; or, if in cooler water (less than 70°C (160°F)), with a detergent suitable for cold-water washing.

Sanitary towels and tampons, or any cloth or material soiled with menstrual blood, should be disposed of immediately. If possible, such material should be tied in plastic bags, then burned or buried. Bandages and other dressings soiled with HIV-infected blood should be similarly disposed of.

10. People with HIV infection should not share syringes, needles, or other skin-piercing instruments, for example, to inject drugs. They should avoid being tattooed or undergoing any other invasive procedure unless sterilization of the instruments can be ensured before and after the procedure.

11. People with HIV infection should not share toothbrushes, blade razors or other instruments that could become contaminated with blood (even though the risk of HIV transmission from these devices is extremely low).

12. HIV-infected people should be actively encouraged and supported in adopting positive health behaviour; the particular form of such behaviour will vary according to social group and country, and will certainly need to be specified to meet the needs of individuals and special situations. It is important to stress to HIV-infected people that they should:

    - Avoid excessive use of recreational drugs, such as amyl nitrates, tobacco, and alcohol. The use of heroin and cocaine should also be avoided. Such drugs may reduce the user's ability to discriminate between safe and unsafe behaviour.

    - Adopt a balanced diet—nutritional deficiencies may adversely influence immune function.

    - Take moderate exercise and get regular sleep—this can add to a general feeling of well-being and contribute to general health and stamina.

    - Reduce stress and try to relax; potential and actual stress factors should be identified and managed.

    - Maintain regular contact with the health care system, including counselling and social services.

13. People with HIV infection or disease usually seek or request information about treatment and possible cures. It is therefore important for counsellors to receive regular and reliable information about the status of research initiatives, and on the availability and appropriateness of specific drugs or therapies for HIV-related conditions. While there is as yet no cure for HIV infection or for AIDS, some therapies have been found effective for treating opportunistic diseases arising from immunodeficiency. At least one drug, zidovudine (also known as AZT), has proved effective in extending survival time and relieving symptoms in some patients. More than 40 drugs (antivirals and immunomodulators) are currently being tested in over 100 clinical trials, mainly in industrialized countries.

14. Many people may assume that expensive treatment or care is necessarily good treatment. Counsellors should be alert to this and help patients make decisions on the advantages and disadvantages of different therapies and interventions.

Counselling should also emphasize socially constructive behaviour and activities that do not involve a risk of HIV transmission. Casual social contact, sharing crockery and cutlery, being in the same room, using swimming-pools and lavatories do not pose a risk for anyone and they help maintain a feeling of social cohesion.

Users of intravenous drugs who are unable to stop should be given information on where they can obtain sterile needles and syringes (if this is possible) or how to use bleach to disinfect equipment used for injection. Some countries or cities have needle and syringe exchange programmes. Drugs are always expensive, and users may engage in prostitution to obtain the money they need. The combination of drug use and prostitution is particularly dangerous for both the prostitute and the client. Special care is needed in counselling those thought to be in such circumstances, in providing condoms, and in encouraging them to insist on their use.

Sex partners of injecting drug users may be at risk of acquiring HIV infection and other diseases if sexual intercourse occurs without the use of condoms. Counselling and information on how to avoid possible HIV infection by adopting safe sexual practices should always be provided for the sex partners of intravenous drug users.

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As the epidemic of HIV infection and AIDS continues to spread, more and more people are having to come to terms with the knowledge that they, or someone they care about, is infected. Such knowledge can impose severe psychological strains, provoking reactions of fear, guilt, depression, denial, anger, and even suicidal activity. In order to deal with these reactions, people need practical and psychosocial support and understanding, together with accurate information on the implications of HIV infection, and particularly about realistic ways of avoiding further HIV transmission. All these can be provided through counselling.

These guidelines provide health workers, counsellors, health managers and others with a model for use in counselling people affected directly or indirectly by HIV. They describe the psychosocial repercussions of HIV infection and disease, the nature, role, and principles of counselling, and special situations in which counselling is called for. The guidelines are intended for adaptation according to the locally available resources and, particularly, the cultural traditions in which they are used.

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